

## Who knows best?

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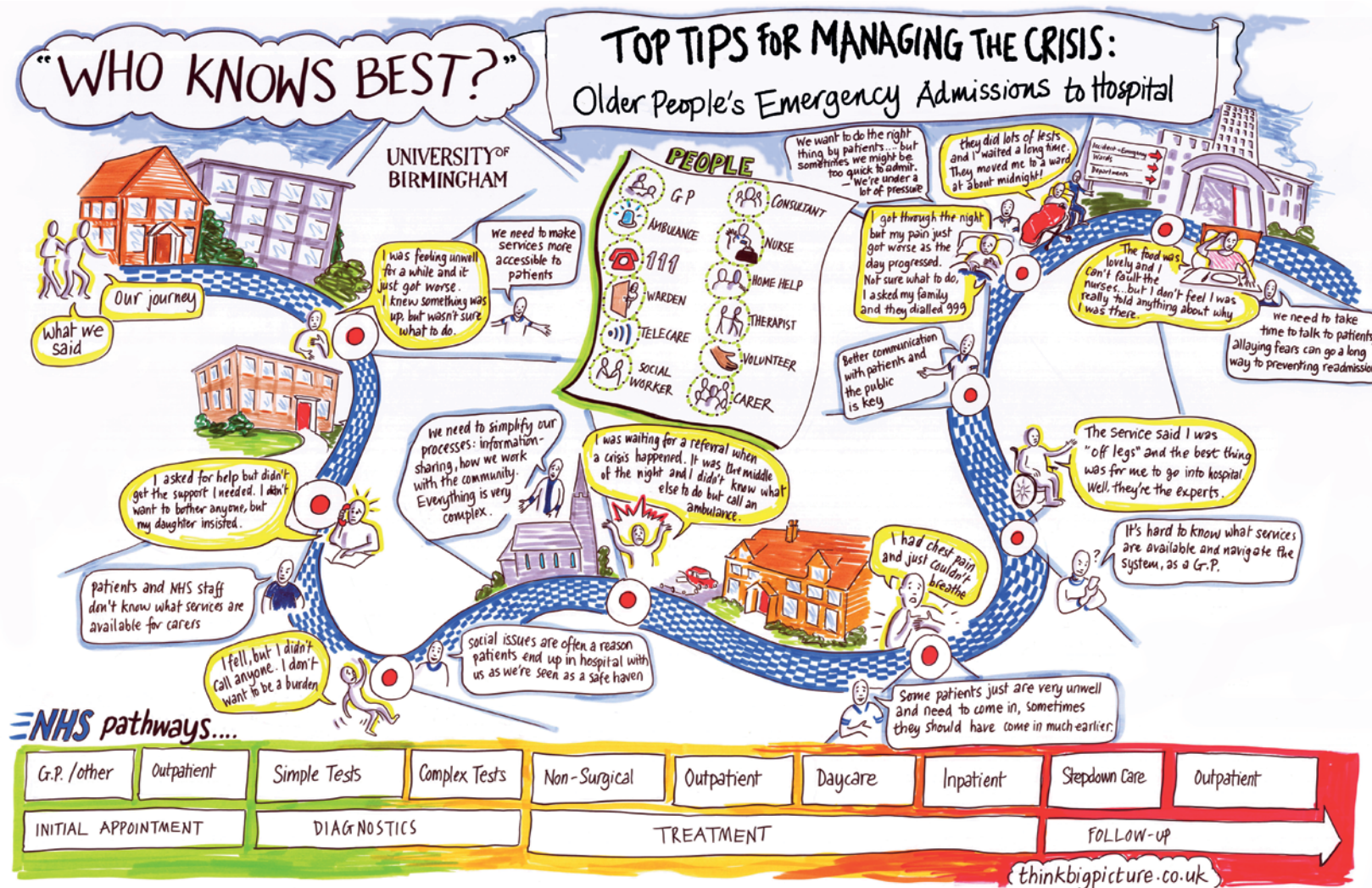
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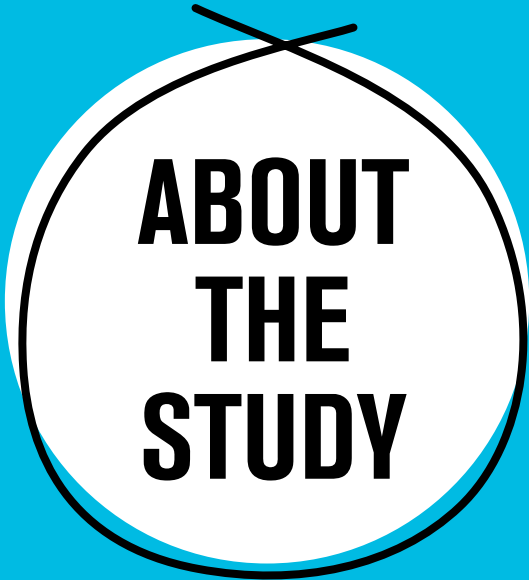
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# ABOUT THE STUDY

This resource is based on a two-year national research project funded by the National Institute for Health Research (Research for Patient Benefit programme - PB-PG-0712-28045). It was conducted by Jon Glasby, Rosemary Littlechild, Nick Le Mesurier and Rachel Thwaites at the University of Birmingham's Health Services Management Centre and Department of Social Policy and Social Work, working with clinical leads in three case study sites:

- Sally Jones, Consultant Physician in Geriatric Medicine and General Internal Medicine, Birmingham Heartlands Hospital, Heart of England NHS Foundation Trust
- David Oliver, President, British Geriatrics Society and Consultant Physician in Geriatrics and Acute General Medicine, Royal Berkshire NHS Foundation Trust
- Iain Wilkinson, Consultant Orthogeriatrician, Surrey and Sussex Healthcare NHS Trust

In total, we interviewed 104 older people or their families within 4-6 weeks of their emergency admission and sent surveys to these people's GPs and a hospital-based doctor (with a total of 45 responses). We also reviewed the previous literature in the UK and beyond, interviewed 40 health and social care professionals and explored the stories of some of the older people who took part in focus groups with 22 local front-line practitioners. This resource is based on the expertise which the older people and their families contributed to the study and the insights that arise from engaging directly with older people (as well as front-line staff).

The project was overseen by a national 'Sounding Board' comprising the partners who have collaborated to endorse this resource:

- Age UK
- Agewell
- The Association of Directors of Adult Social Services
- The NHS Confederation
- The Social Care Institute for Excellence

A 'Social Care TV' video summary is available from [www.scie.org.uk](http://www.scie.org.uk) and the full report is available via the University of Birmingham website (see [www.birmingham.ac.uk/schools/social-policy/departments/health-services-management-centre/index.aspx](http://www.birmingham.ac.uk/schools/social-policy/departments/health-services-management-centre/index.aspx) and [www.birmingham.ac.uk/schools/social-policy/departments/social-policy-social-work/index.aspx](http://www.birmingham.ac.uk/schools/social-policy/departments/social-policy-social-work/index.aspx)).

The study received sponsorship from the University of Birmingham research ethics service and a favourable ethical approval from the Coventry and Warwickshire NHS Research Ethics Committee, as well as support from the Thames Valley & South Midlands NIHR Clinical Research Network and the local Research and Development offices in each of our three case study sites.

The conclusions drawn here are those of the research team and do not necessarily reflect those of the NIHR, the NHS or case study sites.

The images used throughout this document were produced by Laura Brodrick, Graphic and Creative Facilitator, Think Big Picture [www.thinkbigpicture.co.uk](http://www.thinkbigpicture.co.uk).

### What's the problem?

Every year, the NHS experiences more than 2 million unplanned hospital admissions for people over 65 (accounting for 68 per cent of hospital emergency bed days and the use of more than 51,000 acute beds at any one time). With an ageing population and a very challenging financial context, such pressures show no sign of abating – and the NHS is having to find ways of reducing emergency hospital admissions (in situations where care can be provided as effectively elsewhere). However, this is by no means a new issue. For many years, a common concern for policy makers has been that high levels of emergency hospital admissions run the risk of concentrating too many resources in expensive, acute care, leaving insufficient funding to invest in community-based and voluntary sector alternatives and in rehabilitation for people recovering from ill health. Under successive governments, this has led to a series of attempts to develop 'care closer to home' and to make more effective use of hospital beds, recognising that these are scarce resources for which demand outstrips supply.

### Who's to blame?

Often, the assumption in policy and media debates seems to be that potentially large numbers of older people are admitted to hospital without really needing the services provided there, but because there is nowhere else for them to go or because other services are not operating effectively. Depending on the commentator, the culprit may be slightly different – from a lack of social care to difficulties accessing out-of-hours GP care, and from the limitations of community health services to problems with 111 or the ambulance service. In earlier debates, hospitals themselves were the focus of significant blame and mistrust, with suggestions that some older people were being admitted unnecessarily to 'game' NHS access targets and payment mechanisms. However, most accounts are much better at identifying alleged problems than they are at exploring the detail of the claims made or proposing practical solutions.

#### BOX 1 MEDIA COVERAGE OF EMERGENCY ADMISSIONS AND THE PRESSURES FACING ACUTE CARE

“ NHS services outside of hospitals are struggling to cope with growing demand brought on by the ageing population, hospital bed shortages and staff cutbacks ”  
(The Guardian, 2012).

“ Sir Bruce [Keogh – NHS England Medical Director] believes a system-wide transformation is needed to cope with the 'intense, growing and unsustainable' pressures on urgent and emergency care services. ... Every year millions of patients seek emergency help in hospital when they could have been cared for much closer to home ”  
(The Telegraph, 2014).

“ Elderly care is being jeopardised by the increasing numbers of older people being moved to non-specialist wards to clear beds for new patients ” (The Herald, 2013).

“ Nearly two-thirds of the patients now being admitted to hospital are over the age of 65 and many are much older. Their needs are increasing – they are frail and many have dementia. Many arrive in hospital because of a sudden crisis in their health: over the last 10 years, there has been a 37% increase in emergency hospital admissions ”  
(The Guardian, 2012).

### What do we know about the key issues?

In response, there is a growing body of research around what is often termed as 'inappropriate' hospital admissions<sup>1</sup>, with recent studies either drawing on clinical opinion or using more structured clinical review instruments in order to calculate rates of inappropriate admission. However, such studies tend to overlook the importance of local context, do not always draw sufficiently on the tacit knowledge of front-line professionals and, above all, fail to include a patient perspective. The latter is particularly important given that other areas of policy are actively promoting the notion of 'nothing about me without me' and given that older people and their families are the only people with a long-term sense of how their health has deteriorated, what happened to necessitate a hospital admission and what options there might have been at various stages for different interventions and outcomes. Put simply, older people and their families have lived experience of the issues at stake, and we neglect their expertise at our peril.

A good example of this came from our initial pilot study, where professionals tended to focus on issues of 'appropriateness' (was an admission medically necessary?) whereas older people had a more sophisticated notion of 'prevention' (could something have been done differently/earlier to prevent their health from deteriorating to the extent that an admission was required?).

### What's different about this study and this resource?

To our knowledge, this is the first study in the UK to explore the issue of 'inappropriate' hospital admissions from the perspective of older people - and quite possibly the first English-language study to do so internationally. Other areas of health and social care routinely engage people using services in understanding key issues and developing new service responses – it is shocking that no previous research in this area has sought to calculate rates of 'inappropriate' admissions whilst also engaging meaningfully with older people (and indeed front-line staff).

Working with older people and their families, as well as with front-line staff, in three case study sites – our research argues that previous responses and debates have been too simplistic. Reducing emergency admissions is complex, subtle and nuanced – and we should not be surprised if the potential solutions are equally complex and multi-faceted. To help share lessons learned, we have tried to distil the messages from the overall study down into ten key themes (or 'top tips') which could only have been developed by engaging with older people.

While some people would argue that these are just the 'perceptions' of older people and front-line staff, it is often the case that perception is as important as reality, and such perceptions may well have an impact on how people live their lives, how they think of their health and how they access services. This insight could thus be crucial to helping make the current system work, and is a vital source of experience and expertise.

<sup>1</sup> While we don't like this term, it is used in much of the literature – and so we use it here too in inverted commas.



# KEY FINDINGS

(IN BRIEF)

We found no previous study which calculates a rate of 'inappropriate' admission and which engages older people in a meaningful way (in the UK or beyond). Given the importance of user involvement and co-production in other areas of health and social care, this is a shocking finding.

**Most older people in our study were admitted to hospital appropriately. Only nine of our 104 older people (just under 9%) felt that hospital was not the right place for them – and even these people sounded very unwell at the time of admission. None of the GPs or hospital doctors who took part felt that these admissions (or any of the other admissions in our sample) were 'inappropriate.'**

In addition:

- Some people delayed seeking help when a crisis had occurred, and it is possible that negative media headlines about older people's use of NHS resources could deter some people from seeking help in a timely manner.

**SEE TOP TIP 1** ➡

- There was consensus that hospital can remain a default, with the various initiatives set up to reduce the number of emergency admissions creating a complex situation where services are difficult to access in a timely way (for staff, let alone older people).

**SEE TOP TIPS 2 AND 3** ➡

- 'Inappropriate admissions' (whether an admission is deemed medically necessary) is potentially different from 'preventable admissions' (where earlier action could have prevented someone's health deteriorating to the stage where admission was required). This original insight came from older people themselves, who (in our pilot study) seemed to have a more sophisticated notion of prevention than some professionals.

**SEE TOP TIP 4** ➡

- Early action might be required if admissions are to be prevented – once people arrived at hospital and were admitted, it was sometimes difficult for them to be able to leave in a timely manner, and meanwhile, other aspects of their health could deteriorate.

**SEE TOP TIP 5** ➡

- A small number of people felt that a previous hospital stay or assessment might have resolved an underlying problem sooner, without the need for a subsequent admission.

**SEE TOP TIP 6** ➡

- A number of people were in touch with primary and community services (particularly their GP) in the run up to their admission, and the ambulance service was involved in a significant number of admissions.

**SEE TOP TIP 7** ➡

- Social care was largely absent, and staff felt that it needed much more national funding and capacity to be able to play a more preventative role.

**SEE TOP TIP 8** ➡

- People taking part on behalf of family members with dementia felt that some health services are not set up to work well with people with dementia and that social care support is currently insufficient.

**SEE TOP TIP 9** ➡

**Overall, this study argues that older people have a crucial role to play in understanding the issues at stake in terms of emergency admissions.**

**SEE TOP TIP 10** ➡

**Any attempt to generate solutions which does not value and draw on this expertise misses a major opportunity and is unlikely to be successful.**

# 10 TOP TIPS

## 1. Create conditions where older people don't feel they are a 'burden'

Although our research looked at situations where people may not have needed to be admitted to hospital, we found very little evidence of this. Only 9% of the 104 older people who took part felt they did not need to be in hospital, although many of these people sounded very unwell to us when they recounted their stories (see Box 2). No hospital doctor or GP taking part felt that the older person they had worked with had been admitted inappropriately.

Lots of people in our study also sought advice from family or friends, tried to contact their GP surgery for advice and/or waited a period of time (sometimes overnight) in the hope that the pain they were in would stop or that their condition would improve. This included people who lived alone, some of whom left it longer than one day or overnight to seek help. For example, one woman in her 90s had a bout of shingles, but then also fell downstairs. Despite living alone, she did not seek help and it was only when her daughter visited that the woman was admitted to hospital. Another person talked about trying to avoid dialling 999 if at all possible ('just gritted my teeth and waited till I saw a doctor') and about being conscious of being perceived as a potential burden on the health service:

“But I did feel as well – I know having [a] heart problem, whatever, I thought if I'd have had that x-ray and they detected it wasn't a heart attack, I could have come home... Instead of taking beds up.”

A similar sentiment was raised by a family carer who, while discussing his mother's admissions to hospital, felt that she ended up staying in too long on most occasions:

“Yeah, you get her home more quickly. So, yes, but maybe there's underlying things there, we're still testing and you don't know and things might be taking time their side, but it's just a general feeling of, yeah, this bed blocking as they call it in the press.”

Although only a one-off comment, this use of jargon such as 'bed-blocking' and a reference to how these issues are discussed 'in the press' raises at least the possibility that some attitudes to hospital admission (from older people or their family) might be influenced by negative portrayals of older people in policy and media debates.

Rather than older people being admitted to hospital unnecessarily, therefore, the impression was of people trying their best to stay out of hospital and being very aware of the need to make appropriate use of scarce NHS resources. In other settings (for example, in paediatrics), we often encourage families to seek help if in doubt – if it turns out to be nothing serious then this is a great outcome. In services for older people, there may be a risk that people delay seeking help when they should come forward sooner.



## BOX 2: OLDER PEOPLE WHO FELT THEIR ADMISSION WAS INAPPROPRIATE

**Person 1:** began to bleed acutely a week after a haemorrhoidectomy. The patient, on the advice of 111, went to A&E and was told they had been booked in. They were not asked what was wrong and spent a long time waiting in A&E, continuing to bleed. After examination the doctor told the patient the bleeding had stopped and the patient was left alone for a period of time. The bleeding had not stopped, however, and became much worse (with the person's blood pressure dropping severely). This person feels that if they had been seen earlier the bleeding could have been stopped in A&E and they could have gone home.

**Person 2:** felt unable to stand while washing up the dishes and dragged themselves to a chair. The postman arrived shortly after this and called an ambulance. The older person felt they should have been left to come round on their own at home and does not accept the diagnosis of stroke (which they received from the hospital), feeling instead they were 'off legs' due to anxiety and stress.

**Person 3:** was having breathing problems and chest pain. The person's daughter called an ambulance and the patient was taken to hospital. This person feels that the paramedics should have been able to assess how serious the problem was and let them stay at home to recover.

**Person 4:** had been experiencing acute vomiting and diarrhoea and was taken to hospital by a family member as they were in a lot of pain. The patient feels they were not given any real treatment in hospital and that follow-up care was poor – they therefore feel they would have been better being sent home from A&E.

**Person 5:** had been experiencing acute vomiting and diarrhoea and care home staff called an ambulance. This person did not feel the admission was needed as they had experienced similar symptoms before and they had cleared on their own: they felt they were not given a choice.

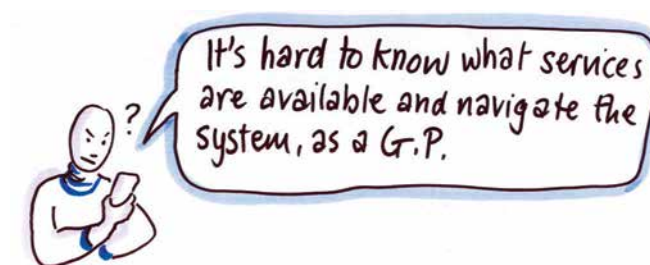
**Person 6:** was fighting for breath, and called 111, who dispatched a paramedic. This person was then taken to hospital and admitted, in part because they have a heart condition and staff were concerned the two were related. However the person's condition settled very quickly and the staff admitted everything they could do to try to investigate the condition had already been explored in previous contacts with the NHS. While the person feels they should have been sent home, tests in the hospital did show up a problem with fluid on the lungs (so the person was nonetheless pleased to have been seen in A&E). The person learned of this fluid after their hospital stay, during a follow-up appointment with their cardiac specialist.

**Person 7:** fell while bringing in the washing and was found by neighbours, who called an ambulance. The patient felt they could have stayed at home to recover or perhaps been taken to a smaller hospital: they did not feel they needed acute care (or to be in such a large hospital). Sadly, this person died shortly after taking part in this study, although we do not know if this was connected with his hospital admission, or not.

**Person 8:** collapsed in the garden and neighbours called an ambulance. The patient understood they were taken in to be thoroughly checked over but contracted a vomiting and diarrhoea bug in hospital and therefore felt it would have been better not to have been admitted but sent home to recover.

**Person 9:** had collapsed a number of times and was admitted for tests. The person's spouse gave the interview as the person is now no longer able to speak for themselves. In hospital, the person's cognitive health and physical mobility deteriorated and they felt no further forward in understanding the problem. Therefore, the spouse felt the older person should have been sent home.

## 2. Community alternatives need to be easier to access



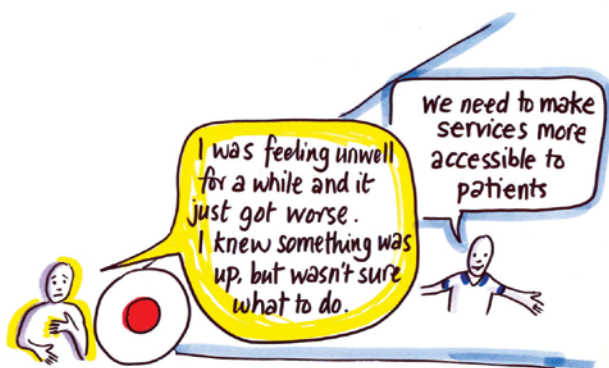
In each of our case study sites, there were a series of community alternatives in place (including both public and voluntary sector services) to reduce the need for hospital admission (particularly rapid response, discharge to assess and specialist nursing teams). However, the perception from many local health professionals was that these services could be very piecemeal and too difficult to access quickly in an emergency. Most people seemed unsure what was actually available, stating that the patch-work quilt of local schemes and initiatives was impossible to understand for most workers, let alone a frail older person in a crisis. As a result, hospital remains a default option – people know where it is, it is always there in an emergency and there can be rapid access to diagnostics, senior decision makers and good quality care:

People just don't know where to go. If you're from a healthcare background, you may have a small chance, but other than that, they've absolutely no idea where to begin. Even the GP surgeries aren't providing them with the information. There doesn't seem to be any public information out there... What if you're just struggling and life is getting harder? No-one knows where to begin.... There's a massive assumption that the elderly person can pick up the phone or has a computer... And once you get through... the telephone waiting time is horrendous. We have clocked up 90 minutes of waiting. (OT)



“We need responsive, credible alternatives outside hospitals for when things are going wrong; so if you’re the daughter, district nurse, GP or a care worker you need to be able to pick up a number and something will happen within the next few hours to assess the person and provide the additional support they need to remain in their own home. All of this could help but they are not mainstreamed and are patchy. We have services which, if we had the capacity, could be used more.”  
(Consultant Geriatrician)

“So we have certain services which are provided for the patients of (names two adjoining areas). They are geographical areas which don’t mirror the geography of the hospital and so you end up trying to make referrals for patients only to be told ‘well, they’re not in our postcode area so we don’t provide this’... You get batted backwards and forwards.”  
(Consultant ED)



### 3. This a two-way process, and hospitals need to play their part



Linked to the notion of hospital as the default, most health professionals talked about the role that community health services and social care could play in reducing the need for hospital admissions. However, this could sometimes feel a very ‘hospital-centric’ view, with the risk that we value partner agencies for what they can do for us, rather than as an important service in their own right with their own priorities, strengths and ways of working. There was less sense in our interviews with staff as to how hospitals were systematically informing themselves, their staff and their patients of what community or voluntary sector alternatives exist, how they were supporting partners to achieve their own priorities and how the hospital might need to adapt its own practices. Sometimes, the issues at stake and the solutions proposed seemed to be ‘someone else’s problem’ – with everyone else needing to do something different (rather than ‘me’ needing to do something different).

### 4. Language matters - there’s a difference between ‘inappropriate’ and preventable admissions

Although the early literature tended to talk about ‘inappropriate’ admissions, a more fruitful avenue may be to focus on ‘preventable’ admissions. This distinction was initially suggested to us by older people themselves, who seemed naturally to distinguish between:

- ‘Inappropriate admissions’ (where someone is admitted to hospital when they do not need the services provided there). Although most of the literature to date focuses on this, our study suggests that the vast majority of older people were admitted to hospital after a crisis in their medical condition, and that hospital was the right place for them.
- Scope for earlier or different action to prevent older people’s health from deteriorating to the extent that hospital is required. It is thus perfectly possible for an admission to be entirely ‘appropriate’, but also to have been ‘preventable.’

However, our experience of recent media and policy debates is that it is easy for these two separate issues to be conflated. We believe that this is a mistake and confuses two different potential problems/two different possible solutions. Diverting people who arrive at hospital but do not need the services provided there might require one set of actions. However, intervening differently and/or at an earlier stage to stop someone’s health from deteriorating is a different type of intervention (and potentially more fruitful).

## 5. Don't leave it too late to explore alternatives

In our study, workers were convinced that early action is needed if admission is to be prevented – and that this needs an experienced, senior decision-maker and a proactive approach. If a junior paramedic came out to a frail older person in distress, for example, they were perceived to be less likely/able to consider alternatives to hospital than a more experienced colleague. Similarly, if a GP was unsure what best to do and encouraged the person to call 999 direct, then opportunities for alternatives were reduced immediately. If it is late afternoon and immediate action isn't taken, then admission may become more likely (with fewer alternatives perceived as being available out of hours).

Once at hospital, there may be scope for initial assessment and diversion to community alternatives. However, the further the older person penetrates into the hospital itself (for example, into Acute Medical Units or beyond), then the less chance there is to avoid a potentially lengthy stay. This was described in terms of entering 'the deeper hospital', where the advantages of specialist medical interventions could be outweighed by risks of loss of independence or of acquired infections. Thus, one of our focus groups talked about an older person who had fallen and been taken to hospital gradually being 'driven into the 'deeper hospital' as each stage of the process wasn't quite sure what to do and referred him on, adding that 'every ward move puts a day on your length of stay.'



## 6. Every contact counts



In public health, recent policy has emphasised that 'every contact counts' (that is, that every time someone accesses a health service, there is an opportunity to talk about the person's broader health and wellbeing and to make a public health intervention). This might well be the same when it comes to admission avoidance. While the older people and the professionals in our study identified few easy answers, they pointed to a potentially large number of contacts with the NHS which could have been used to resolve the older person's underlying health problems once and for all. During our research, a number of people had seen a health professional in the last few weeks, either for routine appointments or as they felt their health deteriorating. We also heard people talk about not feeling listened to during previous hospital stays or A&E attendances, or of professionals seeming to focus on the presenting issue rather than the underlying concerns of the older person:

This time yes, whilst I was taken in and dealt with straight away, the person that was assigned to me to take tests and things just did it for angina which I know I have and the end of the afternoon they said 'Nothing wrong with you. Everything's all right.' They didn't sort of even go into the part of the gall bladder type pain at all. Go home. So I did... and then the next day didn't feel much better so I phoned – they said phone the doctor. So I phoned... my GP and she came out and straight away said 'You must go back because your temperature' ...

None of this is about a single service that could be established or a discrete course of action that could resolve such problems. It's more about a change in mindset which seeks to listen more attentively to older people, which sees their needs more holistically and which is determined to 'get it right first time.'

## 7. GPs and paramedics have a key role to play

If there is scope for prevention, then two key professionals are GPs and paramedics. A number of people in our study were in touch with their GP in the run up to their admission, or tried to contact their surgery for advice immediately before being admitted. Others rang 999 direct and were taken to hospital by an ambulance (or the older person's family rang 999 on their behalf). Very few people rang 111, went direct to hospital, went to a walk-in centre or contacted an out-of-hours GP. Although there were few concrete actions that might have prevented admission, both GPs and paramedics nonetheless seemed the first port of call for many older people, and any attempt to reduce admissions must surely start here.

## 8. Don't neglect adult social care



None of the 104 older people in our study said they were in current contact with a social worker, and few reported receiving social care services in the run-up to their admission or to be waiting for a social care assessment after leaving hospital. We also found it very difficult to recruit people from a social care background to take part in our interviews or focus groups, despite trying really hard. With only one person from social care participating in the study, we were unable to obtain a social care perspective of the issues at stake – although the difficulty we experienced recruiting participants from a social care background may be a case in point of the pressure social care services are under. While this will undoubtedly have influenced the themes we identified, it may also be a finding in itself.

The health professionals who participated in the study felt that social care was crucial, but that it was too over-stretched as a result of national under-funding to be able to play a proactive part in preventing hospital admissions:

“The care agencies don't have enough carers. People are coming out with greater dependency. We need more carers. We have a number of people in the hospital waiting for discharge, and we have no start date. All the time they're in hospital they're losing their independence. And some people, the maximum they will get is four times a day. The carers whizz in for 15-30 minutes, they don't have time to do much for that

individual. We often see people in A&E who have been found in the morning by the carer. There's nothing at night. We also find the ambulance crews get calls to an elderly person who really doesn't have a big health problem but have lost a lot of function, and what they actually need is social care and an emergency assessment to go to respite or an emergency package of care. But there isn't that sense of emergency in the community, so they end up coming to A&E so that we can try and pick it up from there by the hospital social work team. And that's a big problem.” (Community Matron)

“I'll give you a simple scenario, I know a woman who came to the hospital. She was a dementia lady and she was struggling at home; she was being looked after by her husband. He'd been given a contact number for a social worker, he'd been trying to get hold of social services just to arrange some support at home, some sort of care, and he was trying to look after her at home but she was incontinent, she was confused, so he was trying to look after her but he waited so long and didn't get any contact that she had to be admitted. Now that's a scenario where if we had a better service where social input could be provided quicker, that scenario could have been avoided. And she hasn't gone home now; she had to go into a home. If she'd had care in the home environment then that whole scenario could have been avoided.” (Physiotherapist)

In reflecting on this aspect of our research, it could be that widespread funding cuts have led to a lack of capacity to take part in research like this; that emergency admissions are seen as an NHS rather than a social care priority by some front-line staff; and/or that emergency admission is a key threshold and services like social care may only become involved afterwards. However, the fact remains that the role of social care in preventing emergency admissions (and the necessary funding) feel key areas for further exploration (see Box 3).

### BOX 3: THE POTENTIAL ROLE OF ADULT SOCIAL CARE

In reflecting further on these findings, the Association of Directors of Adult Social Services shared emerging themes with its executive group and has drawn out a number of implications for front-line practice:

- Maximise opportunities to promote health and wellbeing and healthy lifestyle choices for older people
- Recognise the importance of supporting older people, carers and families to participate as fully as possible in decisions about them (including hospital discharge plans)
- Ensure that carers are appropriately supported to continue their caring role, with timely information, advice and the promotion of carers' assessments
- Focus on preventing or delaying the development of older people's needs for care and support
- Aim to reduce the needs that older people already have (by maximising independence, quality of life and wellbeing)
- Provide universal access to good quality information about services, including information which reduces loneliness and isolation
- Provide easy access to reablement support, independent living equipment and broader telecare technologies to support older people to maintain or regain their independence
- Work with health colleagues to ensure that older people with multiple long-term conditions are proactively managed in primary care, supported by a range of professionals enabling access to the right care and support
- Provide enhanced coordinated health and care support in the community to prevent unnecessary hospital admissions
- Provide 7 day social work support to assist hospitals to discharge older people every day (including weekends)
- Support timely discharge from hospital, once an individual is ready, through a range of initiatives including voluntary sector services, 'discharge to assess' models, short term care in people's own homes and step-down beds

## 9. Ensure services are set up to work well with people with dementia

A minority of participants in our sample had dementia, but many of their families felt that admissions could be influenced by a perceived lack of awareness of dementia within A&E departments (with the potential for older people with dementia to be admitted in part as a precaution). Often, the older person in question went on to have a long stay, which families felt was not always beneficial:

“I don’t think that week in that particular ward did him any favours, and particularly when at the end of the week I was no wiser, and he was no better.”

“I think the dementia ward is good. But I think the rehab unit, if they’ve got dementia, they give up on them. And the rehab unit had him sent home. They discharge – oh, it was horrendous, actually. They sent him home. The ambulance people had a job – two of them – to transfer him from a wheelchair into his chair, and I said, ‘How am I going to manage?’”

Once older people were given a diagnosis of dementia, social work professionals might have some involvement (although usually only after a crisis had occurred). Typically, however, this input was perceived to be very brief, with long delays in being able to access appropriate support:

“Well, I went on to social services... We’ve still not heard [six weeks later]. I wanted a home visit because... we’re coping at the moment but I need somebody to come and see...”

Moving forward, our national Sounding Board felt that increased dementia care training, the value of dementia friendly environments and the importance of early diagnosis might be key considerations.

## 10. Older people are experts by experience – and we neglect this expertise at our peril

Above all, this resource and our broader study are both based on the belief that older people have a key role to play in understanding and responding to the rising number of emergency admissions. To our knowledge, this is the first study of its kind to calculate a rate of ‘inappropriate’ hospital admissions and to engage meaningfully with older people – and this seems shocking at time when other areas of health and social care are placing such significant emphasis on the notion of ‘nothing about me without me’.

This is both a matter of principle, but also a key practical issue that might be holding us back. As we have argued elsewhere:

“[Previous approaches need] to be accompanied by research methodologies which include and empower the individuals involved. Patients admitted to hospital are often... the best qualified people to talk about their own conditions, the circumstances of their admissions and possible alternatives to hospital... A patient perspective can also provide a more holistic, long-term view of the factors that contribute to hospital admissions, helping to build a picture of how best to respond to the needs of people starting to experience ill-health.”



**This is vital information and insight that tends to reside only with the individual older person and their family. While health and social care professionals can only ever know the person from the moment they walk in the front door, it is older people and their families who have a longer-term sense of how their health has changed, what response they got when they sought help and what might work best for them. Our study is called ‘Who knows best?’ – and we neglect the contribution and expertise of older people at our peril.**

For further national research and policy/  
practice resources, please see:

#### School of Social Policy, University of Birmingham

- Allen, K. and Glasby, J. (2010) *'The billion dollar question': embedding prevention in older people's services – 10 high impact changes*. Birmingham, HSMC (Policy Paper 8)
- Dickinson, H., Glasby, J. et al (2013) *Joint commissioning in health and social care: an exploration of definitions, processes, services and outcomes*. London, NIHR SDO
- Ellins, J., Glasby, J. et al (2012) *Understanding and improving transitions of older people: a user and carer centred approach*. London, NIHR SDO

#### ADASS

- ADASS (2010) *Supporting people to live and die well: social care at the end of life*.
- ADASS (2012) *The case for tomorrow: facing the beyond – a joint discussion paper on the future of services for older people*. ADASS/Institute of Public Care
- ADASS (2015) *Distinctive, valued, personal: why adult social care matters – the next five years*.

#### Age UK

- Age UK (2015) *Caring for someone with dementia: a practical guide to help you*.
- Age UK (2015) *Social care assessment, eligibility and care planning (factsheet 41)*.
- Commission on Dignity in Care (2012) *Delivering dignity. Securing dignity in care for older people in hospitals and care homes*. Independent Commission on Dignity in Care (a collaboration established by the NHS Confederation, the Local Government Association and Age UK)

#### NHS Confederation

- NHS Confederation (2013) *Ten priorities for action to improve the care of acutely ill patients*. NHS Confederation press release, 18/7/2013
- NHS Confederation (2016) *Growing old together: a report by the independent Commission on Improving Urgent Care for Older People*.
- NHS Confederation (2016) *Growing old together: what the evidence tells us*.

#### SCIE

- SCIE (2008) *Helping you through a hospital stay: advice from older people* (produced in partnership with Age Concern and the Alzheimer's Society).
- SCIE (2013) *Maximising the potential of reablement*.
- SCIE's *Prevention Library* ([www.scie.org.uk/prevention-library/](http://www.scie.org.uk/prevention-library/)).

SCIE has also played a key role in producing NICE (2015) guidance on *Transition between inpatient hospital settings and community or care home settings for adults with social care needs*.



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